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DOI:

[10.3109/09638237.2015.1101424](https://doi.org/10.3109/09638237.2015.1101424)

Document Version

Publisher's PDF, also known as Version of record

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Citation for published version (APA):

Ashcroft, J., Wykes, T., Taylor, J., Crowther, A., & Szmukler, G. (2016). Impact on the individual: what do patients and carers gain, lose and expect from being involved in research? *Journal of Mental Health*, 25(1), 28-35. <https://doi.org/10.3109/09638237.2015.1101424>

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To cite this article: Joanne Ashcroft, Til Wykes, Joseph Taylor, Adam Crowther & George Szumukler (2016) Impact on the individual: what do patients and carers gain, lose and expect from being involved in research?, *Journal of Mental Health*, 25:1, 28-35, DOI: [10.3109/09638237.2015.1101424](https://doi.org/10.3109/09638237.2015.1101424)

To link to this article: <http://dx.doi.org/10.3109/09638237.2015.1101424>



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Published online: 06 Jan 2016.



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ORIGINAL ARTICLE

Impact on the individual: what do patients and carers gain, lose and expect from being involved in research?

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Abstract

Background: Study feasibility and deliverability can benefit from involving patients and carers in the research process, known as patient and public involvement (PPI). There is less evidence on the experiences of patients and carers themselves and we require more information across a range of studies, health conditions and research stages.

Aims: This study explored how patients and carers in eight diagnostic research specialties have been involved in research, their motivations and the impact involvement had on them.

Method: 143 patients and carers across the Clinical Research Network (CRN) responded to an online semi-structured questionnaire (developed using participatory methodology). Quantitative and qualitative data were analysed.

Results: A range of benefits were reported, including providing a life focus and an improved relationship with illness. Less positive experiences regarding time and money and lack of acknowledgement were also reported, along with suggestions for improvement.

Conclusions: PPI confers many benefits on patients and carers which could increase PPI recruitment if made explicit. More involvement in study recruitment and dissemination would increase the effectiveness of PPI input. Involving a more varied socioeconomic demographic and at an earlier stage is vital. Financial support for lower earners and greater feedback following involvement should also be explored.

Keywords

Carers, Clinical Research Network, healthcare research, patient and public involvement, PPI, research involvement, service users

History

Received 19 March 2015

Revised 9 September 2015

Accepted 11 September 2015

Published online 15 December 2015

Introduction

Researchers increasingly endeavour to involve patients, carers and the public in their research, a process known as patient and public involvement (PPI). This involvement can take place at any stage of the research process, including advising on research priorities for funding, being a member of a project steering committee and disseminating research findings. Those involved in PPI activities are active partners in research, as distinct from 'participants', the passive subjects of a research project (Barnes & Cotterell, 2011).

Public involvement in research has been underpinned by policy and guidance in the NHS since the 1990s (Minogue et al., 2005). Funding and supporting NHS research, the National Institute for Health Research (NIHR) expects researchers to engage with PPI and requires a PPI plan with

each funding application (Staley et al., 2013). This applies across the NIHR Clinical Research Network (CRN), a comprehensive network for health research across England which offers logistic support for the set up and delivery of research studies (Darbyshire et al., 2011).

A strong moral case can be made for involving patients and carers in healthcare research (Szmukler et al., 2011). An increasing number of reviews highlight evidence demonstrating benefits of PPI to research outcomes (Boote et al., 2012; Brett et al., 2010; Staley, 2009). PPI helps ensure findings are genuinely useful for patients and carers (Staley et al., 2013), helps identify research questions (Wykes, 2003), helps shape or reshape study design (Wykes, 2014; Wykes & Marshall, 2004), increases study success by enhancing recruitment (Carter et al., 2013; Coupland et al., 2005; Ennis & Wykes, 2013; Faulkner, 2006), provides insights that may transform data analysis (Rose, 2004; Rose et al., 2008), and may elicit better and fuller information from study participants (Gillard et al., 2012). In addition to benefits to the research, personal benefits to the researchers themselves as a result of the PPI process have been reported in the Medical Research Council Trials Unit (Vale et al., 2012).

Much less is known about the impact of PPI on the patients and carers themselves. In a wide-ranging review, Staley (2009) found those involved in PPI activities benefited from

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new skills and knowledge, personal development, support and friendship, enjoyment and satisfaction, but also sometimes emotional burdens, negative media exposure and frustrations about not being involved more fully. However, these reports were based on informal, retrospective information in small studies (Barber et al., 2011). Some retrospective accounts of engagement in action research are available, primarily in mental health (Bryant et al., 2012; Hitchen et al., 2011; McDaid, 2009), but also cancer (Cotterell et al., 2011), palliative care (Bellamy et al., 2011), drug services (Coupland et al., 2005) and dementia (Law et al., 2013). Although covering a range of conditions, these accounts are of involvement in single projects only. A limitation in drawing conclusions from previous PPI literature is posed by non-standard approaches to defining PPI and a failure to state explicitly at which stage of research members of the public were involved (Shippee et al., 2015).

The present study focussed on the experiences of patients and carers across the CRN portfolio, asking specific questions about the extent of involvement in research, motivations for getting involved and the impact that this had on the individuals. In doing so, it aimed to improve on previous studies by sampling large numbers of patients and carers to gain a broader picture of their PPI experience across a range of studies, health conditions and stages in the research process. This was important given that it is not clear whether the benefits previously described in the field of mental health are generalised to other conditions. It is only if they are that we can suggest sharing good practice across disorders.

Method

Design

This study was a mixed method, cross-sectional self-report survey, utilising a semi-structured questionnaire containing closed questions and text boxes for further explanation.

Participants

This was a convenience sample of patients and carers associated with the eight extant disorder themes in the NIHR CRN (Cancer, Comprehensive, Dementias and Neurodegenerative Diseases (DeNDRoN), Diabetes, Medicines for Children, Mental Health, Primary Care, and Stroke). Each network invited participants using their particular communication systems. Participants were offered the opportunity to enter a prize draw to win a £25 Amazon voucher in return for completing the survey.

Measures

A draft survey was developed in a collaborative partnership between researchers, patients, carers and PPI staff across the NIHR CRN and was piloted with 28 patient and carer volunteers. The results of the pilot were used to shape a final structured questionnaire, which included seven open-ended sections. The survey contained questions on specific examples of research involvement, motivations for becoming involved and the experience of being involved in terms of understanding research and health

issues, relationships with others, skills development, health and wellbeing, and time and money.

The survey was administered online using SurveyMonkey (SurveyMonkey Inc, Palo Alto, CA). Those who participated in the pilot study were not included in the findings reported here.

Statistics

Quantitative analysis of the closed questions using McNemar χ^2 tests was supported by the software package SPSS for Windows (IBM Corp. Version 20.0, 2011, Armonk, NY). Qualitative free text responses were analysed using inductive thematic analysis (Braun & Clarke, 2006) supported by NVivo software (QSR International Pty Ltd. Version 10, 2012, Doncaster, Australia). The qualitative analysis was conducted by only one researcher (JT), although the ‘‘themes’’ with illustrative example quotations were discussed with GS and JA.

Results

143 individuals responded to the survey (this was 84% of all responders; 27 of 170 were omitted because only the first item was completed): 77 women, 53 men (13 declined to state their gender) who were aged between 55–64 years. There were no significant differences in age between the different research specialities. The majority (125 respondents) identified as white British, 2 as Asian/Asian British, 1 as mixed/multiple ethnic, 4 as other (11 respondents failed to disclose their ethnicity). The responses were from across the disorder themes, with the majority being from the Mental Health and Cancer specialities. Web Table 1 of Appendix displays how respondents were involved in research and other activities across the research specialties. Of the 143 respondents, 69 were service users, 29 were both service users and carer, and 32 were carers. Most closed questions (58%) had no missing data. Of the items with missing data most were less than 10% with only six items having up to 20% missing data.

Timing of involvement

The majority (82%) of respondents were involved in activities contributing directly to improving the feasibility of study delivery in advance of the study taking place (Web Table 1 of Appendix). Significantly fewer (64%) were involved in the delivery stages of research projects (McNemar $\chi^2(1, N = 143) = 11.0, p = 0.001$), and even fewer (50%) were involved in engagement and dissemination activities (McNemar $\chi^2(1, N = 143) = 32.6, p < 0.001$). A majority (58%) were involved in activities to promote PPI.

Involvement in research related activities

The most common other activities were attending seminars and events as a representative of the CRN (48%), attending training days organised by the CRN (48%), and being a member of a PPI involvement group promoting the value of PPI (47%).

Thematic analysis

Responses to the open questions ranged between 7% and 52%. The highest frequency of responses were to questions

concerning the impact of the research on the person (37%), and positive and negative experiences during their involvement (52%), and “any other comments” (32%). The quotations come from these responses. The thematic analysis of the free text responses resulted in 45 codes, which were grouped into four themes: motivations for involvement, benefits of PPI, barriers to PPI, and the experience of being involved (see Figure 1 of Appendix for a full list of themes). The qualitative results help to elaborate the quantitative findings and unearth additional information.

The results that follow report the responses to closed question items that applied to these themes first and then the qualitative data follow.

Motivations for involvement

As seen in Table 1 of Appendix, the majority of respondents identified with largely altruistic motivations for getting involved in research: putting knowledge gained from being ill or caring to good use (81%), making a difference to diagnosis, treatment and service delivery for others (76%), and giving something back to the NHS (56%). Another motivation reported by the majority of respondents was to feel useful (55%). The lowest reported motivations were gaining financial income (9%) and improving skills or gaining work experience (29%).

The wish to gain personal meaning from the experience of illness and to contribute to something useful for others was widely stated. Many people set out to ensure patients and/or carer perspectives were explicitly represented, to shape research into what patients and carers want. A number of carers expressed the need for the carer position to be represented distinctly from the patient:

Because, as a carer, I think carers’ involvement in research is under-rated compared to service user involvement, and I would like to help redress that balance. Carers are beginning to feature in research, but usually bracketed together with service users as if the issues for both are the same. They’re not.

A smaller number stressed the importance of working in an equitable partnership, in contrast to working in a purely consultative capacity.

Benefits of PPI

A significantly greater number of respondents rated PPI as having a positive impact on their lives rather than a negative impact, for all but two of the issues surveyed (McNemar χ^2 in all cases $p < 0.01$; Table 2 of Appendix). More people also said that research involvement had a positive impact rather than being a drain on financial income and time, but the difference was not significant.

Three sub-themes characterised the benefits of PPI: psychological and social benefits, improved relationship with illness and crisis, and intellectual benefits.

Psychological and social benefits

The majority of those who made free text comments reported psychological benefits from involvement, which in many cases had a transformative effect:

Being involved in my CRN has restored my self-esteem and self-confidence, and motivated me to take on challenges that I would have not believed possible 5 years ago.

Many people expressed high levels of satisfaction and enjoyment from involvement in research. Working in an equitable partnership and being valued were common reasons:

More than anything I feel I have had an impact, generally beneficial for others. That level of satisfaction is often hard to achieve I have found over the years.

Providing a life focus and meaning was commonly cited as a positive, “recovery focused” benefit of taking part in research. This was identified in some cases as being particularly important in facilitating a successful transition into retirement:

Retired from the NHS 2 years ago, involvement has helped ‘wean’ me off work, giving me some focus which needs me to engage my brain. I find it interesting and have met a lot of lovely people along the way.

Social benefits from meeting others were identified by a large proportion of those who responded qualitatively. A number of respondents made friends, and in some cases gained other benefits from working with the research teams:

Mixing with the Clinical Studies Officers (they’re all young) helps to keep me young - in mind if not in body!

Improved relationship with illness and crisis. In many cases, involvement in research helped people make sense of and come to terms with their illness, provided them with meaning and insight, and transformed their relationship with their illness, with a sense that something positive had come out of the negativity of diagnosis and treatment:

I have enjoyed being part of things and it has given new meaning to my life and helped when I was feeling down. It has helped me communicate again with the world.

Involvement in research acted as a forum for peer learning and support on many levels: speaking with others who had lived with the illness to understand the experience, feeling less alone with the illness by becoming part of a group, and learning more about the illness from clinicians in a setting with a new clinician-patient power balance. Being treated well by clinicians helped people with their treatment and in some cases fostered a new respect for clinicians.

Carers gained a lot from speaking to other carers in terms of mutual support and helping them to care better:

But it is also hugely helpful to me personally to spend time with other carers who understand what it’s like being a carer for someone with mental health problems. And I

think what I am learning in the group is helping me to care better too.

Intellectual benefits. The majority of intellectual benefits related to gaining and developing skills and interests. A rehabilitative effect was gained from redeploying existing skills and expertise in a new context, those undergoing long-term treatment enjoying the opportunity to put these skills to use despite being unable to work and developing a closer relationship with the NHS in the process. Many respondents gained a greater understanding of research. Some noted that becoming involved in research catalysed a transition to paid work:

Kept me busy - which is good. Plus been an important part of getting me back to more paid work than I would have imagined.

Others were inspired to pursue further research and study:

PPI has given me the experience and courage to try new things, so much so, that I am actually taking an MSc in Social Work.

Barriers to PPI and suggestions for overcoming them. The majority of comments relating to researchers and clinicians were positive. A small number reported that some clinicians and researchers are not on board with PPI and have negative attitudes to it, although this is changing. In some cases, it was thought that clinicians and researchers need to do more to understand the position of those engaged in PPI activities in terms of their enthusiasm, time, money and capacity, bearing in mind their illness. In a minority of cases respondents felt that clinicians were dismissive of the effort and support available in the PPI teams and individuals. A larger number of respondents reported feeling underused and not recognised for the skills they could bring.

Others were frustrated that they cannot offer more time. Time and money in some cases were identified as barriers to involvement, although only a small number of respondents thought that payment was necessary or expected.

A number made the point that information was given to them too late to enable them to properly engage, taking into account that it is often not their "day job" and they often have problems relating to their illness to contend with.

Others asked to be involved earlier in the process to help decide what research should be done, and to be offered encouragement to get involved with writing-up or publication of findings. In many cases the general point was made that PPI was not set up for patient or carer led research.

I believe that PPI should be "tightened up" to have full collaboration in research (which is where it works best) rather than some researchers' interpretation of it being just consultative.

Communication, in particular complicated technical language and jargon, was commonly flagged up as a key barrier

to effective engagement, alienating some and being suggested as a barrier to others. In some cases, it was felt that expectations and roles should be clarified.

Negative comments were made regarding the composition of the patient and carer groups involved in research. In many cases group members were viewed as the "usual suspects" and "self-selecting" and respondents recognised the need to improve diversity and recruitment to PPI groups in particular, to better involve minority ethnic groups and people with low income. In other cases, it was felt that people too close to their diagnosis were not able to offer constructive input:

Some people involved in PPI seem only interested in their own particular area or situation, particularly so when they are recently bereaved. I think the RNs need to be mindful and careful about this when recruiting for PPI.

A number of suggestions were made around spelling out the benefits of involvement to would-be recruits on a personal level, and in one case a personal request to be involved in recruiting participants was made.

A number of comments were made on the need to retain some kind of overarching national PPI group, helping with co-ordination and sharing best practice.

The experience of being involved

Table 3 of Appendix sets out responses to specific questions on the PPI experience. The majority of respondents (over 80%) answered positively to questions on whether they had been treated with respect, able to speak up, listened to, and made to feel valued, and had taken part in meaningful activities most of the time or always.

The free text responses were somewhat more ambivalent, but still largely positive. Many references were made to being well supported, part of a good team, feeling useful, valued and respected. In many cases people felt they were listened to. However, some people expressed concern over how their contributions had been factored into the research, with a number of people receiving little or no feedback.

Some reported the experience of being involved tokenistically on occasions but more fully in others, with others noting a progression over time to more meaningful involvement. There was some frustration about the length of time taken to make decisions during the PPI process and the slow progress made in achieving results but this seemed to be improving with time.

In a much smaller number of cases people felt overwhelmed due to the pressures of the work, the weight of the issues being discussed, the attitudes of clinicians, the power balance, and the confusing language being used.

Discussion

Of the patients and carers who responded to the survey, a high proportion were involved at early stages in the research process, indicating that the CRN is involving patients and carers as active collaborators, in line with INVOLVE's more empowering definition of PPI. This finding is reinforced by personal accounts from respondents describing a shift from tokenistic to fuller involvement.

Respondents reported a number of benefits of PPI, including an enhanced understanding of research, building relationships, personal development, improved health and wellbeing, and enjoyment and satisfaction, in line with the findings of Staley (2009). Positive impacts that have been less described previously included easing the transition into retirement and making people better carers. Many of these benefits accrued from the provision of a forum for peer learning. With high satisfaction levels all round it was not possible to determine whether involvement at later stages was less satisfying. Fewer people reported being involved in dissemination activities, and it is suggested that the CRN could usefully consider whether more could be done in this area.

A number of ‘‘emancipatory’’ benefits came about through involvement providing a revised life focus, including a chance to come to terms with illness and to feel less ‘on the scrap heap’ by redeploying skills. These findings support the approaches of pioneering organisations such as ResearchNet (Springham et al., 2011) who are involving patients and carers in research as a means to support recovery as well as enhance research.

In line with other studies (Bellamy et al., 2011; Coupland et al., 2005; McKeown et al., 2012), respondents in this study reported largely altruistic motivations. In addition, respondents identified specific motivations to represent the patient position and to represent the carer position as separate, in line with the findings of Brosnan (2013) and Kara (2013).

A small number of respondents were motivated to take part in research for personal development reasons. However, a large proportion reported receiving training and attending seminars; potential PPI members may not have been aware at the outset that they could obtain these benefits. Few were motivated by financial gains. The CRN: Mental Health pays people for taking part in PPI activities. Other research specialties were more variable in this regard, although most paid travel expenses. The issue of payment is controversial, not least because payment, for some, may be seen as devaluing their involvement for altruistic reasons (Lowes et al., 2011). Time and money were identified as constraints, but were not as motivational as satisfaction and enjoyment. Some respondents were involved because they wanted to make a difference *in spite* of losing time and money. The sample may have been over-represented by very altruistic PPI members or those who could afford to sacrifice time and money. Those unable to afford the time and money perhaps did not respond to the survey, or were not involved in CRN research. This is an issue that warrants further investigation.

Our findings suggest that the CRN could encourage PPI involvement from groups that may not be so altruistically motivated by focusing on benefits of involvement they were not expecting, such as training and getting into employment. Those on low incomes also need encouragement when money is a significant barrier to PPI activities. At the very least they should not lose out. We may then see more varied involvement across the sociodemographic and ethnic minority spectra. More work should also be done to build on requests from the respondents for involvement in recruitment, exploring whether patients and carers can reach out to others who may not yet be engaged in research.

Coupland et al. (2005) and Law et al. (2013) found that ‘‘being asked’’ was a key factor in engaging people in PPI.

The present results support those benefits of PPI to patients and carers and related challenges highlighted in ‘‘good practice guidelines’’ on PPI recently published by the Clinical Research Network: Mental Health (2014), such as building skills to aid employment and feelings of empowerment and accomplishment despite a diagnosis of mental illness. There is a need to ensure that efforts are made to further mitigate the reported negative aspects of involvement. These included people being overlooked, underused and in some cases overwhelmed, although such experiences were scarce in this sample. A key point is a lack of feedback and an inability to see how their contribution had made a difference. This seems to have a negative impact on the power balance between researchers and patient collaborators and the extent to which members of the public are empowered or meaningfully involved (Staley, 2009; Trivedi & Wykes, 2002). Clinicians and researchers could also benefit from giving more credit to the contributions of those engaged via PPI, and attempt to better understand their positions. It is important to value those engaged in PPI, involve them early and ensure that communications and language are clear and not excluding. People must be given enough time to digest information before contributions are required.

Whilst there may be different experiences of impact associated with characteristics such as age, gender, ethnicity, or sexual orientation, they were not apparent in this study. Further work is needed to explore how representative the present sample was of those engaged in PPI activities in the CRN as a whole, and indeed whether those engaged in PPI represented the full range of patients and carers. McLaughlin (2010) discussed the issues related to this. There is almost certainly a need to improve representative recruitment to PPI groups: our sample was heavily skewed towards a white ethnicity, aged 55–65+.

The key limitation in this study was the sampling. The number of respondents was not sufficient for comparisons to be made between the CRN research specialties. However, the results show a general similarity in their experiences of PPI among service user and carers across the specialties where the numbers responding were highest. In the two larger samples, mental health and cancer, so different in the nature of the illnesses researched, the similarities were in the main readily apparent. This provides some support for the generalizability of the findings across medical specialties.

It was not possible to test for an association between the stage of engagement and satisfaction levels because satisfaction levels were very high across the board. It could be that those who responded to the questionnaire overrepresented those with positive views. This could also have been confounded by the differences in CRN research speciality and the power relationship between patients and carers and service providers. Differences in numbers between the research specialties could be influenced by a wide range of factors: different numbers of patients and carers actually involved in PPI, an unwillingness or inability for some people to respond to the survey, the funding and time available for engaging with PPI activities, and the strategy of disseminating the

questionnaire used by each research speciality. Some respondents did voice a view that PPI is patchy across the research specialities, and that best practice should be shared between them. The larger numbers from mental health and cancer might reflect that PPI in the former was relatively better funded by the CRN as it was seen as particularly challenging, while the latter had the longest history as a research network and had strong charitable support. The establishment of the Mental Health Research Network probably benefited from the growth in the mental health service user “voice” which grew at the same time. Influencing the research agenda was seen by many as an important way of shaping studies in directions that were meaningful for the end-users.

This study has highlighted a number of important benefits of PPI. Further work to explore how these benefits are expressed across the different research specialities is important, as the mechanisms and motivations need to be understood before it is possible to encourage better representation and involvement. Differences between patients and carers also need exploration as carers in particular have called for a differentiation. Motivations for involvement may be dissimilar. It is also important to understand the satisfaction at different stages of involvement, to test whether earlier involvement is associated with greater satisfaction, a claim made in previous research studies and included in policy documents.

Despite the relative paucity of knowledge about carers, motivations for involvement and satisfaction at each involvement stage it is clear that there have been dramatic advances in the field of service user involvement and the learning particularly from the most developed areas – cancer and mental health needs to be shared across disease areas. Best practice will need continued development (Mawn et al., 2015; Trujols et al., 2013) which will also need a continued commitment by research funders and funded coordination if research is to continue to benefit from user involvement.

Declaration of interest

The authors have no conflicts of interest to declare. Til Wykes acknowledges the support of the NIHR Biomedical Research Centre at the South London and Maudsley NHS Foundation Trust and King's College London and her NIHR Senior Investigator Award.

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Appendix

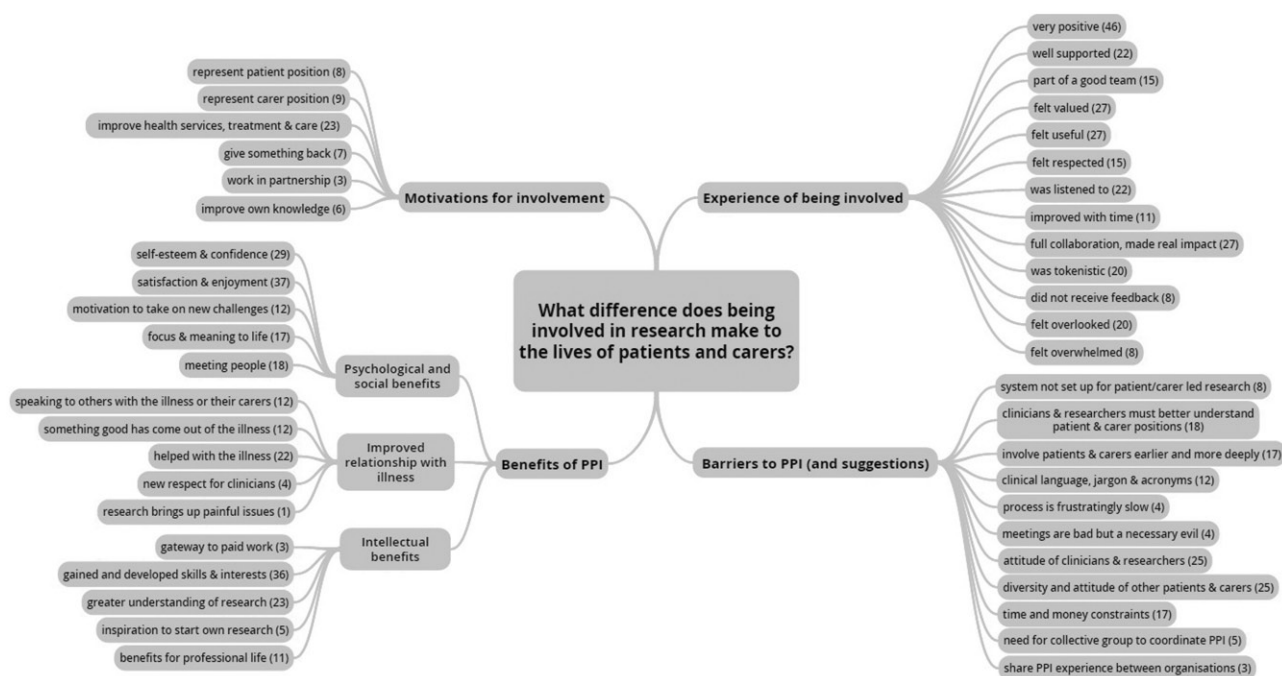


Figure A1. Themes and nodes (numbers in brackets are numbers of occurrences).

Table A1. Motivations for research involvement.

	Cancer (N = 37)	Comp. (N = 18)	Dementia (N = 12)	Diabetes (N = 4)	MFC ^a (N = 10)	MH ^b (N = 47)	PC ^c (N = 3)	Stroke (N = 8)	Other (N = 4)	Total (N = 143)
Put knowledge and experience of being ill or caring to good use	81%	72%	83%	75%	90%	81%	67%	88%	100%	81%
Make difference to diagnosis, treatment and service delivery	78%	50%	83%	100%	80%	81%	67%	63%	75%	76%
To feel useful	48%	50%	67%	50%	20%	70%	67%	50%	25%	55%
Give something back to the NHS	62%	56%	42%	75%	50%	49%	67%	63%	100%	56%
Meet others	57%	28%	42%	50%	30%	62%	0%	38%	100%	50%
Gain a better understanding of certain health problems	49%	11%	75%	75%	50%	49%	0%	50%	25%	46%
To challenge assumption research is academically/clinically led	43%	11%	25%	25%	40%	43%	0%	25%	25%	34%
Improve skills or gain work experience	27%	11%	8%	25%	20%	47%	0%	25%	50%	29%
Gain financial income	11%	0%	0%	0%	0%	17%	0%	0%	25%	9%

^aMedicines for children, ^bMental health, ^cPrimary care

Table A2. The impact of being involved in research.

N = 143	Big negative	Negative	Neither positive nor negative	Positive	Big positive	N/A	Missing
On understanding of issues							
Health problems, diagnosis & treatment	0%	1%	14%	43%	33%	1%	8%
Research	0%	0%	7%	49%	38%	0%	6%
Health services	0%	4%	16%	51%	21%	1%	7%
On relationships							
Professionals met through research	0%	1%	6%	50%	35%	0%	8%
Patients and/or carers met through research or collaboration	0%	1%	13%	38%	35%	5%	8%
Organisations (such as universities) met through research	0%	0%	15%	42%	24%	10%	9%
People for whom you have a caring responsibility	0%	0%	19%	24%	12%	33%	12%
Your caregiver	0%	0%	19%	13%	9%	44%	15%
Your clinician	0%	1%	28%	28%	15%	16%	12%
On personal development							
Development of skills	0%	0%	15%	50%	24%	2%	9%
Improving employment prospects	1%	1%	23%	18%	10%	37%	10%
On health and wellbeing							
Physical health	0%	3%	47%	25%	8%	7%	10%
Mental health	0%	2%	33%	34%	18%	4%	9%
Self-esteem	0%	2%	17%	48%	20%	4%	9%
Having a social support network	1%	3%	30%	38%	13%	5%	10%
Taking on structured routine activities	0%	2%	35%	25%	15%	11%	12%
On time and money							
Financial income	4%	13%	46%	14%	4%	11%	8%
Time	4%	16%	37%	26%	8%	2%	7%
Overall impact	1%	1%	8%	59%	24%	0%	7%

Table A3. The experience of being involved in research.

N = 143	Never	Rarely	Sometimes	Most of the time	Always	Missing
Were you treated with respect?	0%	0%	6%	32%	54%	8%
Were you able to speak up and express yourself easily?	1%	1%	6%	35%	49%	8%
Were you listened to?	0%	1%	14%	33%	44%	8%
Were you made to feel valued?	0%	3%	15%	33%	41%	8%
Were the activities that you participated in meaningful?	0%	1%	12%	41%	37%	8%

Web Table A1. Involvement in research and other activities.

	Cancer (N = 37)	Comp. (N = 18)	Dementia (N = 12)	Diabetes (N = 4)	MFC ^a (N = 10)	MH ^b (N = 47)	PC ^c (N = 3)	Stroke (N = 8)	Other (N = 4)	Total (N = 143)
Improving feasibility of study delivery	89%	78%	92%	75%	80%	79%	67%	75%	75%	82%
Develop patient/carer info, consent or clinical documents	82%	44%	58%	50%	70%	53%	33%	75%	50%	62%
Develop or influence protocol	60%	50%	25%	25%	40%	43%	0%	50%	0%	44%
Identify recruitment issues & strategies	60%	39%	33%	50%	40%	38%	33%	50%	50%	45%
Identify or prioritise research topic/question	51%	28%	33%	50%	70%	38%	0%	63%	25%	43%
Develop or influence research methods/tools	49%	28%	42%	50%	10%	47%	33%	63%	50%	43%
Identify ethical issues	49%	28%	17%	50%	50%	36%	0%	63%	25%	39%
Co-applicant on a funding bid	43%	11%	8%	0%	10%	11%	0%	50%	25%	21%
Develop PPI involvement plan/budget	46%	11%	25%	25%	0%	30%	67%	38%	75%	32%
Involvement in project delivery	81%	56%	50%	100%	40%	60%	33%	75%	75%	64%
Member of PPI advisory group	54%	50%	33%	50%	20%	43%	33%	38%	50%	44%
Member of a study steering committee	38%	28%	33%	25%	20%	45%	0%	63%	25%	37%
Member of a trial management committee	51%	0%	8%	0%	0%	6%	0%	25%	25%	18%
Collection of data or implementation of intervention	11%	0%	0%	25%	0%	28%	0%	13%	25%	14%
Engagement and dissemination activities	54%	50%	33%	0%	20%	57%	33%	63%	75%	50%
Giving presentations at conferences	32%	6%	17%	0%	10%	32%	0%	13%	25%	23%
Disseminating findings to public or professionals	24%	17%	8%	0%	10%	28%	0%	25%	50%	22%
Evaluating PPI activities in the research project	22%	17%	17%	0%	10%	26%	33%	13%	50%	21%
Writing lay summary of research findings	16%	22%	17%	0%	0%	19%	0%	38%	25%	18%
Analysis or interpretation of data	14%	0%	0%	0%	0%	21%	0%	13%	25%	12%
Co-authoring a journal article	22%	11%	0%	0%	0%	9%	0%	13%	0%	11%
Writing progress reports or bulletins	11%	6%	0%	0%	0%	15%	0%	0%	25%	9%
Involvement in activities to promote PPI	70%	44%	42%	75%	60%	51%	67%	75%	75%	58%
Participating in a CRN management/strategy committee	41%	0%	25%	0%	20%	19%	67%	25%	25%	23%
Writing guidelines/reports related PPI	27%	11%	0%	25%	10%	17%	0%	0%	0%	15%
Promoting the value of research	49%	22%	25%	50%	30%	30%	33%	50%	25%	35%
Promoting the value of PPI on behalf of a CRN	54%	22%	33%	75%	40%	30%	33%	75%	75%	41%
Contributing to the information provided on CRN website	24%	0%	17%	25%	0%	15%	0%	25%	25%	15%
Contributing to CRN news bulletin	13%	11%	0%	0%	0%	17%	33%	25%	25%	13%
Involvement in other activities	75%	61%	92%	75%	70%	72%	100%	100%	50%	75%
Attend seminars/events as CRN representative	68%	33%	33%	50%	20%	45%	0%	75%	50%	48%
Attending training days organised by CRN	65%	22%	42%	75%	30%	49%	67%	25%	50%	48%
Patient and carer involvement group	46%	33%	58%	50%	50%	47%	67%	63%	25%	47%
Sitting on a CRN staff interview panel	8%	0%	8%	0%	0%	11%	0%	13%	0%	7%

^aMedicines for Children, ^bMental Health, ^cPrimary Care